

Genetic Services Section: Complaint/Inquiry Log For Use by the Washington State Genetics Task Force

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Date	Provider/Consumer Location	Clinic/Lab Insurance or Other	Scenario	Issue	Follow-up
11/20/91	Consumer Bellingham	Other	Woman w/ HHT, wants to know what activities the state is engaged in re: the HGP, wants to establish support group.	Need for consumer education/resources	Letter sent describing GSS and efforts. Woman encouraged to join PacNoRGG
12/5/91	Consumer Seattle	Other	Woman w/ 12 yo son w/ San Fillipo, threw TV at 2 yo brother – Mom wants permanent placement for affected son.	Lack of long-term care facilities for children/adults w/ severe health/behavioral problems	No residential options, able to get DSHS to provide respite care
12/20/91	Consumer	RGC Clinic	Woman seen at metabolic clinic, felt she was treated badly and asks for referral elsewhere.	Need to evaluate/strengthen quality assurance measures.	W/ pt's permission, contacted Dr. and GC – they will follow-up w/ pt. She was informed next nearest clinic at OHSU or Vancouver BC.

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2/28/92	Provider/Consumer Spokane	Other	Pt sent confidential information to GSS as requested by her MD.	Need for provider education/resources	Contacted pt, informed her that info being returned to her MD. Sent letter to MD educating about AFP screening and availability of gc services in area.
3/13/92	Consumer Everett	OB Clinic	Father of woman whose fetus found on U/S to have a probable heart defect. States woman given no counseling or referral and family is distraught.	Need for provider and consumer education/resources	Spoke w/ man re: benefits & limitations of U/S, variation in heart defects, suggested they contact their OB and ask for a referral to UW or Swedish perinatal

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5/11/92	Provider Issaquah	Other	GC upset that GSS denied her application for a MAA prenatal dx genetic counseling provider number		GC failed to meet criteria and has no plans to alter her practice in a way that would enable her to meet the criteria.
9/11/92	Consumer Puyallup	Insurance	Woman states she was denied auto insurance due to fam hx epilepsy. She's never had a seizure	Genetic discrimination	Given OIC complaint number and sent OIC complaint forms.
10/2/92	Consumer Everett	OB Clinic	Couple learned in 3 rd tri that fetus has Tri18. No apparent counseling although supportive midwife – parents feel “pushed” to induce labor, ignored, no referrals for counseling made.	Lack of appropriate genetic counseling - Need for provider education/resources	Couple sent materials about Tri 18, local support group info, letter encouraging them to speak w/ their providers and a listing of RGCs.
10/13/92	Consumer Seattle	Other	Seeking info (genetic, health referral and support) Batten's disease and Marfan syndrome.	Need for consumer education/resources	Letter sent w/ listing of RGCs
10/28/92	Provider/CHRM C Seattle	Other	Seeking info on available support groups for genetic disorders	Need for consumer education/resources	Sent listings available
11/13/92	Consumer Bothell	OB Clinic	U/S in 3 rd Tri showed fetus w/ MCA likely Tri13 – Mom wants gc & to know organ/research options	Lack of appropriate genetic counseling - Need for provider education/resources	Spoke on phone and sent letter to mother along w/ listing of RGCs should she wish further counseling.

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2/4/93	Consumer Walla Walla	Other	Woman concerned her hx of miscarriages and infertility a result of Hanford	Need for consumer education/resources	Put in touch with Hanford info line at Fred Hutchinson
5/3/93	Consumer Kent	Clinic	Parents of 10 yo boy dx by local neurologist w/ Tourette syndrome – seek more info & referral for 2 nd opinion and genetic eval	Lack of appropriate genetic counseling - Need for provider education/resources	Spoke on phone and sent letter w/ referral info as well as support group info
6/23/93	Consumer & Provider Yakima	RGC Clinic	Foster family of infant removed from care of mother immediately after birth due to heavy crack cocaine use. Foster family seeking eval and counseling re: special needs of drug exposed infant	Need for continuing education of genetic service providers and social service providers	Referred to Yakima RGC, contacted NAPARE for most recent data, shared written materials w/ GC
6/23/93	Consumer Tacoma	Other	Son w/ chondrodystrophica myotonia – seeks other families for support	Need for consumer education/resources	RGCs contacted, 3 other families in state – GCs to contact to see if they'd be willing to speak with the Tac. Family. Letter sent to family along w/ national support group info.

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11/13/94	Consumer Tri-Cities	Insurance	Preg. woman seen for GC (reason not specified) and payment for services denied by insurer.	Insurer's refusal to pay for genetic services	Provided consumer and provider info on filing complaint to OIC and citing RCW 48.21.244 and WAC 246-480.020. Received letter from insurer 3/25/94 that they have changed their policy accordingly.
5/17/94	Consumer Olympia	Insurance	Man w/ fam hx of HD denied life insurance	Discrimination practices in insurance industry	Given OIC complaint line although explained insurers can deny applicants based on fam hx of disease and other reasons
5/18/94	Provider Seattle	Insurance	GC forwarded a letter received from insurer granting pre-authorization for gc, but not if provided by their MS trained GC (must be MD).	Lack of insurance industry recognizing the qualifications of a board certified GC	Filed letter
6/22/94	Consumer (lawyer) Tacoma	Other	Lawyer of couple w/ newborn w/ DS seeks published standards of care states woman AMA and not offered amnio	Lack of genetic counseling - Need for provider & consumer education/resources	Referred to ACOG, ACMG, ISONG, MOD and NSGC for policies re: prenatal diagnosis
10/7/94	Provider Tacoma	Other	Neurologist believes a pt of his has HD, asks about doing MRI to dx	Need for provider genetics education/resources	Educated re: avail of DNA testing and GC, referred to UW
11/8/94	Consumer/Provider	Insurance	Preg woman received gc for AMA but insurer denied the claim.	Insurer's refusal to pay for genetic services	Provided consumer and provider info on filing complaint to OIC and citing RCW 48.21.244 and WAC 246-680
11/24/94	Consumer/Provider Seattle	Insurance	Pregnant woman received gc for AMA & insurer denied payment. GC and consumer upset.	Insurer's refusal to pay for genetic services	Provided consumer and provider info on filing complaint to OIC and citing RCW 48.21.244 and WAC 246-680

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3/7/95	Consumer/Provider Seattle	Clinic	Preg woman seen for gc, brought w/ her a copy of questionnaire provided by MD's office – she was concerned about an “anti-abortion policy” she had to sign.	Ethics of MD s having pts sign in advance that they “accept” a policy of no referral for elective termination procedures even if abnormality detected.	Contacted WA Chapter of ACOG – knew of this clinic and policy, but had no suggestions for addressing.
4/11/95	Consumer Bellevue	Insurance	Man w/ Marfan syndrome denied life insurance	Discrimination practices in insurance industry	Given OIC complaint line although explained insurers can deny applicants based on fam hx of disease and other reasons
4/17/95	Consumer Seattle	Other	Man seeks DOH's “position” on “human experimentation” given HGP – concerned about cloning	Need for consumer education/resources	Letter sent clarifying role of DOH and IRB criteria

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5/24/96	Consumer Lacey	Lab/Other	Man w/ HgB AS dx w/ failing kidneys, his MD says due to the trait. His parents were tested and neither has the trait. Wants to be able to accurately counsel his kids.	Need for provider genetics education/resources	Letter sent – referral to Dr. Mark Walters @ Odessa Brown Sickie Cell clinic w/ cc to PCP
6/10/96	Consumer (lawyer) Tacoma	RGC Clinic	Seeking documentation of DOH genetic policies/quality assurance. Family suing due to 2nd child born w/ Fragile X - they would not have pursued preg had they known their son's condition was genetic.	Need for consumer education (personal responsibilities)	Documentation provided. Family lost case. RGC had tested and counseled appropriately for the time, family failed to keep follow-up appts.

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1/8/97	Provider Seattle	Lab	Neurologist confused – told by lab his pt didn't need gc at UW for HD testing, he could submit sample directly – he did. Then pt kept UW appt, another sample submitted. Lab says pt tested previously – no info that pt has been told results.	Unclear testing protocols resulting in confusion to providers & multiple tests ordered by different providers	Met in person w/ lab director to discuss policies and procedures.
1/8/97	Consumer Sunnyside	Fam Prac Clinic	Woman had presymptomatic HD test thru PCP. States her MD gave her lab report and said she has the gene but MD not sure he knew how to interpret and gave her UW clinic number. She called but got an answering machine.	Lack of adequate genetic counseling by provider – need for provider education/resources	W/ pt's permission, called GC at UW who will get copy of lab results and contact woman directly
1/27/97	Provider Spokane	Lab	RN feels her efforts to help MDs and pts by ensuring pts get gc before testing is undermined by lab staff who tell MDs they can submit samples directly –w/o gc.	Unclear testing protocols resulting in confusion to providers, possibly leading to lack of pre-test genetic counseling	Brought issue to CLAC – labs
1/29/97	Provider ??	Lab	Neurologist upset that family received genetic test results before he did – family received by having their PCP call lab, got results and shared w/ family	Lack of post-test genetic counseling	No action taken
2/7/97	Provider Seattle	Lab	GC upset re: possible lab sample mix up (pt appeared positive for HD but mother was negative). Family from SW WA so collection of additional samples arranged locally.	Need to evaluate/strengthen quality assurance measures to ensure no sample mix up	Met in person w/ lab director to discuss policies and procedures.

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2/11/97	Provider/Consumer Seattle	Lab	Pt of above case contacted lab and informed of possible sample mix-up – provider and consumer upset.	Inappropriate communication to family – need to evaluate/strengthen quality assurance measures.	Met in person w/ lab director to discuss policies and procedures.
12/16/97	Consumer Arlington	RGC Clinic	Couple seen due to fam hx Fragile X – not happy with lack of attention to their concerns by GC	Need to evaluate/strengthen quality assurance measures.	W/ permission of couple, contacted GC who will f/u w/ family

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1/20/98	Consumer Kennewick	Other	Mother of 4 yo girl born w/ CL/CP, who was grateful for the genetic services she received. She's upset to learn that the Tri-cities clinic is closed and asks DOH to help support opening a new clinic	Need for additional resources to support genetic services in rural areas.	Letter sent explaining decision to withdraw support until community identified resources to help sustain a genetics clinic.

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No entries for 1999					

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12/8/00	Consumer Seattle	Lab	Father of girl w/ MR who died recently seeking chrome results from state cytogenetic lab (testing done in 1980).		Letter sent w/ copy of lab results, original sample and slides destroyed years earlier.

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3/20/01	Consumer & Provider	Insurance	RGC provider and pt concerned about TRICARE policies re: genetic testing. Mother of boy w/ symptoms of muscle weakness, and fam hx Emery-Driefuss muscular dystrophy wants testing for son but insurer denies.	Need for health plans/insurers to establish reasonable policies re: medical genetic services	Letter sent to TRICARE Northwest sharing work done by GSS re: health plan policies and genetic services as well as a sample medical policy.
11/16/01	Consumer & Provider Seattle	Insurance	Preg woman seen for gc (reason unspecified) and insurer denied the claim.	Insurer's refusal to pay for genetic services and lack of licensure for GCs	Provided consumer and provider info on filing complaint to OIC and citing RCW 48.21.244 and WAC 246-680. Level 1 appeal denied – insurers cites GC not a licensed provider under RCW 70.127 as required by pt's contract.